

NEWSLETTER

AIDS NETWORK OF EDMONTON

May/June 1988

Volume 3 No.5

Royal Society reports

AIDS: A PERSPECTIVE FOR CANADIANS

In April the Royal Society of Canada released its report entitled "AIDS: A Perspective for Canadians", undertaken following a request for advice from the Federal Department of Health and Welfare. Scientists of the Royal Society studied the medical, social, ethical, legal and economic aspects and their impact and significance of AIDS in a Canadian context. The wide ranging report includes many recommendations for federal and provincial governments, the public, concerned groups and health care professionals. Cooperation and initiative is the underlying theme of the report: ad hoc efforts are simply not enough to deal with the complex issues AIDS poses.

The report is cognizant of the limited resources of the Canadian health-care system and the steadily growing challenge of AIDS. Recommending federal and provincial cooperation in the establishment of a system for the care of those infected with HIV infection, the report places emphasis on the need for adequate home and hospital care, comprehensive counselling and follow-up, as well as concern for health-care professionals and social support for people with AIDS.

The Society had much to say about the legal implications for AIDS, urging stringent standards of confidentiality and recommending legislation prohibiting discrimination. Careful and considered use of voluntary and anonymous testing is recommended, as well as amendments to provincial laws to allow anonymous

testing for research purposes. The scientists, believing the AIDS epidemic not a national emergency, gave little credence to mandatory testing of defined groups such as prison populations, hospital patients, immigrants, students, teachers and others employed in schools. They also recommended that there be no general isolation or quarantine of HIV sero-positive people or people with AIDS.

Across the board education with evaluation is recommended for everyone from defined groups to the general workplace, and especially all health-care personnel.

(continued next page)

INDEX

Summer Travels	Page 3
AIDS - Effects on the Brain	Page 4 & 5
Education Consultant Hired	Page 6
Volunteer News	Page 6
NETWORK Support Services	Page 7
Upcoming Events	Page 7

Greater and more co-ordinated educational efforts and initiatives are needed;

"In the absence of an effective vaccine or treatment, educating the public about the nature of the disease, its modes of transmission, methods of prevention, and its association with risk activities must be the mainstay of efforts to modify and retard the spread of the epidemic."

It is noted, as well, the effectiveness of well-crafted educational campaigns that reach targeted groups offering alternatives and prompting motivational and attitudinal changes.

"The San Francisco AIDS Foundation has found that a person must hold several beliefs before it is likely that his or her behavior will change: AIDS must be believed to be a personal threat, and it must also be believed that AIDS is preventable by the adoption of satisfying and achievable new behaviors that will be supported by peers."

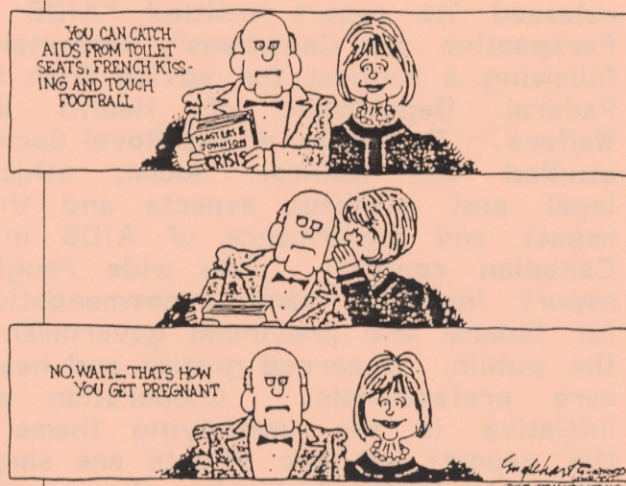
Existing community based health promotion and educational initiatives are credited with this country's low prevalence of HIV infection, however the Society recommends up to \$80 million per year be spent on greater and more co-ordinated educational efforts and initiatives. The Society does note that more needs to be known about the effectiveness of educational campaigns.

Given all of the above, the Society strongly advocates increased AIDS-related research and a multidisciplinary approach in the areas of clinical epidemiology and public health-care policy research. A large multi-wave survey of adult and adolescent Canadians is needed to provide currently lacking information about sexual practices, ideas, feelings and behavior relevant to the spread of sexual diseases, and trust in various sources of information. The Society also calls for an increase in the number of people involved in AIDS research, emphasizing that the lack of human resources will seriously impede

AIDS-related research and health care. The Society suggests that the total budget for all AIDS and HIV research should be at least \$35 million per year, a substantial increase over the \$8.91 million spent in the past two fiscal years!

Complete copies of this report are available for \$4.00 each from:

The Royal Society of Canada 1988
344 Wellington Street
Ottawa, Ontario
K1A 0N4



Ross Armstrong Office, 2nd Floor, 10704 - 108 Street,
Edmonton, Alberta T5H 3A3
(403) 424-4767

AIDS NETWORK OF EDMONTON

APPLICATION FOR MEMBERSHIP

Name: _____

Address: _____

City: _____ Postal Code: _____ Phone: _____

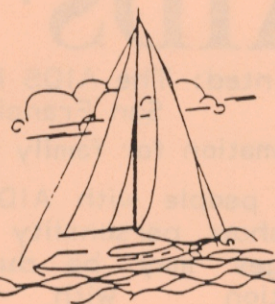
A \$25⁰⁰ membership entitles the undersigned to discount admission at specified AIDS NETWORK events, regular newsletter mailings, and the right to vote at AIDS NETWORK meetings.

Signature: _____ Date: _____

Please notify the AIDS NETWORK if your address changes.

Please enquire about the reduced membership rates for students or the unemployed.

Summer travels



Travelling to other parts of the world this summer? The following article is reprinted from the Globe & Mail's travel column, January 30th, 1988.

Noting that AIDS is spread by sexual activity, contaminated blood and from mother to child at birth, Dr. Mann says that the vacationer need have no fear of contracting AIDS by sitting next to an infected person -- even if that person happens to be sneezing or coughing -- or from sharing a cup or plate. Being bitten by blood-sucking bugs is no cause for alarm. On the other hand, improperly sterilized ear-piercing equipment -- the type of tools you might expect to find in a bazaar -- and dirty acupuncture needles are accidents looking for places to happen.

The advice on injections is: steer clear of them unless absolutely necessary. "If you must have an injection, make sure the needle and syringe are new." Watch as they are removed from an unopened package. If this is not possible, make certain the instruments have been cleaned and properly sterilized in boiling water for about 20 minutes. Packing a set of needles and syringes "just in case," might seem to be a solution, but unless you have a prescription or a doctor's note, this practice is to be avoided. Customs and police officers tend to associate needles with illicit narcotics.

On the safety of blood transfusions, WHO is tentative. It advises the use of screened blood, but says that an ounce of prevention is worth a ton of cure.

How do you avoid the need for a transfusion?

As far as WHO is concerned, it's pretty clear that road accidents provide the greatest need for blood transfusions among travelers. So it says, "Wear seat belts; don't drink and drive; drive with care; learn to say slow down or stop in the local language."

While advising the usual sex-related precautions -- the proper use of condoms and avoidance of sex with prostitutes or casual acquaintances "even in countries that may claim to be free of AIDS" -- the WHO calls on travellers to maintain psychological preparedness.

Travel encourages a sense of liberation from workday cares and responsibilities. The cruise romance syndrome is a fact; behaviour that might seem inappropriate at home suddenly feels appropriate. But "AIDS is a factor worldwide," says Dr. Mann. "There are no safe zones."

A few countries, such as Iraq, require HIV tests even for tourists. The NETWORK can provide you with information about which countries are currently requiring AIDS tests.

Group facilitators needed

Facilitators of support groups are needed. Professionals with interest in this area who possess either group-work skills or individual counselling skills are invited to contact the Co-ordinator of Support Services at the NETWORK.

AIDS' effects on the brain

Reprinted: The AIDS Health Project
San Francisco, California

Information for family and care givers

Some people with AIDS become confused or show personality changes. These changes may be due to direct brain infection with the human immunodeficiency virus (HIV), the cause of AIDS. Or they may also result from such causes as: anxiety, depression, medication, or a treatable illness related to AIDS.

About half of those with AIDS or ARC develop signs of brain involvement during their illness. Many of these signs are due to a cause other than HIV infection of the brain. Only a physician can diagnose the underlying cause of these changes. If a person with AIDS develops the problems described in this pamphlet, it is essential to seek immediate medical evaluation.

"Many other medical and emotional problems can cause the changes described below and may respond to medication if correctly diagnosed."

When to Suspect Brain or Other Nervous System Involvement

Unlike most other brain infections, signs of HIV involvement may progress slowly and gradually. Forgetfulness, emotional instability, or "just behaving differently", may be early signs of HIV dementia, a progressive inability to perform normal tasks. Be alert for:

SYMPTOMS AND SIGNS:

- forgetfulness (misplacing objects, forgetting recent events and familiar names, losing track of time)
- difficulty concentrating (can't focus on conversation, is easily distracted)
- mental slowing (not as "quick" as usual)
- impaired judgement (impulsive behavior, poor decision-making)
- personality changes (apathy, withdrawal, irritability)
- mood changes (extreme "highs and lows" anxiety, emotional outbursts, rage)
- psychotic behavior (hallucinations, paranoia, grandiose thoughts)
- leg weakness or hand tremor
- impaired coordination (clumsiness, deteriorated handwriting)

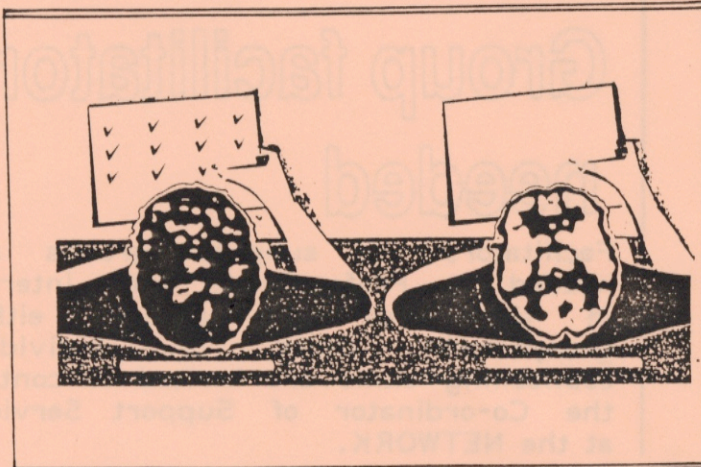
As the disease progresses, affected people may become increasingly confused and develop severe memory loss. They may eventually become unable to perform simple tasks and increasingly weak and lethargic.

Each person experiences these changes at different rates, and NOT EVERYONE develops all of these manifestations. Many people function well for long periods of time, whereas others develop severe difficulty within a few months. Sometimes symptoms appear to improve for hours or days, producing a "good-day/bad-day" course.

Accurate Diagnosis is the Key

Many other medical and emotional problems can cause the changes described and may respond to medication if correctly diagnosed. The first step is to contact the person's physician. Only a complete medical evaluation can rule out the possibility of treatable illness. Some common treatable AIDS-related conditions include depression, anxiety, nutritional deficiencies, infections, recreational drug use and side effects of medication.

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PSY. TODAY - JUNE 1988

How to Help

People with HIV dementia are not always in control of their actions. If you become frustrated, try to remember that the sick person is not deliberately trying to make you angry. He or she is demonstrating a need for support. Here are some things you can do to help:

Orientation: Individuals may forget where they are, lose track of time, and eventually not recognizing family or friends. To decrease periods of confusion, it is helpful to provide:

- familiar objects, such as photos, and personal belongings.
- gentle reminders about the year, month, date, time and place. Calendars and clocks are helpful.
- signs or pictures that highlight important considerations, such as turning off the stove or pointing the way to the bathroom. A low light left on at night to orient the person and light the way to the bathroom.

Structure: Changes in routine and environment further increase confusion and distress. To create structure and reduce anxiety:

- provide a consistent, predictable living situation.
- keep the person's belongings in the same place at all times.
- avoid sudden changes in daily routine or give the person only one task to do at a time.
- encourage self-reliance, but keep your expectations realistic.

Communication: People with HIV dementia often cannot process information or respond rapidly. Be patient, and don't confront or argue with the person. To decrease frustration:

- present information slowly, broken down into one step at a time.
- ask questions that can be answered simply, preferably with a "yes" or "no".
- don't assume that the person understands everything being said: have the individual repeat instructions, and observe to be sure that he or she understands.

- have the person keep track of things by writing them down, if possible.

Stimulation: Too much or too little stimulation can increase confusion, fearfulness, or agitation. To avoid this:

- keep social gatherings small and scheduled at regular intervals. Large groups may prove overwhelming.
- provide assistance with hobbies or pleasurable activities.
- notify the doctor if constant agitation is a problem. Medication may help decrease agitation when used properly.

Safety: Confused or disoriented people should not be left alone. Lock up medications and other dangerous substances. Persons who talk of suicide or who are severely depressed require immediate medical evaluation.

Future Horizons

Though there is currently no cure for HIV dementia, much can be done to help the person maintain control and cope with the disease. Certain new antiviral drugs are currently being evaluated to determine whether they benefit people with HIV nervous system involvement. For now, you can best help those with HIV dementia by insuring proper diagnosis, setting realistic expectations, and providing a structured, caring environment.

In memoriam

It is with deep sadness that we note the passing of Randy McKay on May 1st, 1988. Randy made the transition at home, in the presence of friends and his partner, Tom. A memorial service was held on Friday, May 6th. Randy was a social worker and a member of the first Board of Directors of the AIDS Network of Edmonton Society. Our sympathy is extended to his family and lover.

We also note the passing of Richard on May 22nd, 1988. Our sympathy is extended to his family and lover.

Education consultant contracted

The NETWORK has hired an education consultant, Nandini Kuehn, to evaluate our current educational programming and make recommendations for future endeavors.

Nandini has been hired for three months, and her final report will be completed by the end of July. Part of her work will be to contact other agencies and organizations involved in AIDS education. She will also assess future needs in the community and recommend which educational programs the NETWORK should undertake. She hopes that other agencies can be encouraged to initiate programs in their area of expertise, with the NETWORK taking on more of a consultative role.

Nandini is recently from San Francisco, where she lived for 10 years. She was working at the University of California when they began to see people with AIDS in 1981. Her formal education as a health care administrator and her background as an education consultant to the US Public Health Service and the California State Office on AIDS will be a valuable asset to her current project with the NETWORK. She has worked with the San Francisco AIDS Foundation, the AIDS Health Project (publisher of Focus), and Project AWARE - a landmark research program on Women and AIDS.

If you would like to have input into future educational activities, or if you want to give feedback on current programs, you are welcome to call Nandini at the NETWORK office, 424-4767.

Volunteer news

WELCOME!

We would like to welcome to the NETWORK volunteer corp an enthusiastic group of newly trained volunteers including Bob, Anne, David, Kelly, Al, Marg, Mike, Carlyle, Cecile, Neil, David, William, Theresa, Wade, Lisa, Leonard, Nancy, and Rose.

VOLUNTEER INSERVICE EVENING

Our regular monthly volunteer inservices will continue throughout the summer months. Specific topics of relevance to volunteers will be presented by resource people. The July inservice will be on Wednesday, July 06 at 7 p.m. at the NETWORK office. The topic will be Legal Issues Regarding AIDS.

TOUCHING BASE EVENING

This is an opportunity for volunteers to come together informally to socialize and air any general volunteer concerns. On June 21st, the volunteers have formally challenged the staff and board members to a baseball match and picnic.

BUDDY SUPPORT MEETING

Volunteers presently providing emotional support to a PWA are invited to the next buddy support meeting on June 29th.

FAREWELL AND HELLO!

Diane Caryk, our Assistant Co-ordinator of Volunteers will be moving on to new challenges after May 31 when her PEP position expires. Diane's contribution to managing the volunteer program has been greatly appreciated. We'll miss her smile! Doris Rank will move into this position for the summer until she returns to college in the fall. Doris has persisted sometimes against many hurdles, in her efforts to establish a recreation program for PWA's.

NETWORK SUPPORT SERVICES

Of all the work undertaken by the NETWORK, Support Services is possibly the least known activity. It is however a major component of the NETWORK's services to people affected by AIDS. Our services augment those provided by the medical community in meeting the practical and psycho/social needs of the client. By way of advocacy, networking and initial intervention we hope to assist individuals and their partners, friends and family gain access to the information and agency service, which will help them maintain a high quality of life and make appropriate plans and set priorities. This is achieved through staff maintaining an ongoing contact with individuals and volunteer involvement. There is a constant need for individuals to discuss their issues and concerns, gain information and maintain contact with supportive people. Through our volunteers, support groups and staff we are able to respond to these needs and be the sounding board many people seek.

The NETWORK is the first contact for many people after a diagnosis has been received or a concern has been raised about health status. We provide the safe environment most needed at this time. As other issues arise the NETWORK continues to function and assist individuals in making decisions, answering questions and dealing with fear. The support groups allow for issues and concerns to be expressed with others going through the same experience.

The Buddy volunteers and other practical/emotional support volunteers provide the extra assistance so many individuals need. Information about community services is provided by the staff and advocacy is performed as needed. As far as possible we encourage and support individuals to maintain control over their lives.

Decision making and planning need to remain an individual's right. We seek to provide options and supports so that an individual is capable of making the best decisions and the most productive plans to maintain the highest quality of life possible.

—Upcoming events—

JUNE:

If You Think My Closet is a Mess, You Should See My Fridge! - a look at homophobia and self-oppression. A Public Forum during Gay and Lesbian Awareness Week - June 27th at 7:00 p.m., Humanities Bldg, Lecture Theatre 1, University of Alberta Campus. EVERYONE WELCOME

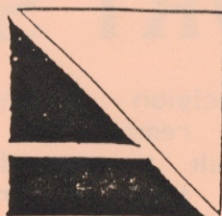
Other events include a booksale, dance, picnic, ecumenical church service and evening open houses at Womonspace and Community Centre offices.

JULY/AUGUST:

Conference: Companions on the Journey Dignity National Conference for gay and lesbian Catholics and friends. At MacEwen Hall, University of Calgary Campus, July 29th - August 1. Events include keynote speakers, panels, workshops, liturgies and social events. Topics will address a whole range of issues affecting this community including: AIDS and Spirituality; AIDS and Community; Pastoral Care for PWA's. Registration deadline July 1, 1988. For more information contact Dignity Edmonton - Phone 469-4286 or write Calgary Conference 1988, Box 4213, Station C, Calgary, Alberta, T2T 5N1.

Office Address:

10704 - 108 Street
Second Floor
Edmonton, Alberta
T5H 3A3



Telephone Number:

Info Line: 429-AIDS

Business Line: 424-4767

Office Hours:

Monday - Friday 9 a.m. - 6 p.m.

INFORMATION LINE HOURS

Monday - Thursday 9 a.m. - 9 p.m.

Friday - 9 a.m. - 6 p.m.

Saturday - 12 Noon - 4 p.m.

The Newsletter is published monthly by the AIDS Network of Edmonton Society with financial assistance from the HEALTH PROMOTION DIRECTORATE OF HEALTH AND WELFARE CANADA. The AIDS NETWORK of Edmonton Society, incorporated in February, 1986, is a registered non-profit charitable organization (Reg. # 0747212-11-25).

ROSS ARMSTRONG MEMORIAL FUND

UPDATE: May 22nd, 1988

ROSS ARMSTRONG TRUST FUND:

Donations:	\$4,813.35
Memberships	\$4,050.00
Interest:	\$ 204.67
Subtotal:	\$9,068.02
Grants:	\$5,092.32
Service Charge:	6.25
NET	\$3,969.45

The AIDS Network of Edmonton Society, incorporated in February, 1986, is a registered non-profit charitable organization. The mandate of the AIDS NETWORK is to provide education about AIDS to the high-risk groups and the general public, support to individuals with AIDS and ARC and co-ordination of services for individuals with AIDS/ARC.

INFORMATIONAL: An informational and support line operates Monday - Friday, 9 a.m. - 9 p.m. A leading resource library is available to agencies and the public.

EDUCATIONAL: A speakers' bureau provides speakers for Educational presentations to concerned groups. Audiovisual materials and information files are available on loan.

COUNSELLING: Confidential one-on-one counselling services are available to persons directly or indirectly concerned about AIDS. Referrals to other professional services are made upon request.

SUPPORT GROUPS: For persons who have tested positive for HIV Antibodies. For persons with AIDS. Friends, families, and partners of persons with AIDS.

ADVOCACY: Assistance will be provided to individuals facing difficulties in receiving services because of their health status.

The AIDS NETWORK works to coordinate the services of supportive public and private agencies in all areas involved by the AIDS crisis.

The services of the AIDS Network of Edmonton Society are provided FREE and on a CONFIDENTIAL bases.

CANADIAN
AIDS
SOCIETY



LA SOCIÉTÉ
CANADIENNE
DU SIDA

THE AIDS NETWORK of Edmonton Society is a member of the CANADIAN AIDS SOCIETY/LA SOCIÉTÉ CANADIENNE DU SIDA